

The ethics of data utilisation: a comparison between epidemiology and journalism

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Legal controls over data collection in European countries have badly affected the work of epidemiologists. By contrast, journalists have been allowed far greater freedoms. The aims and tasks of both professions are in line with accepted values in our society—especially those of inquiry and the benefits of an open society. Society seems willing to accept that, in the interests of wider public good, journalism may sometimes invade individuals' privacy and do them harm, but it is not prepared to offer epidemiology an equal measure of tolerance.

Laws covering procedures of data collection have adversely affected the prospects for epidemiology, especially in countries with previously favourable conditions for epidemiological research, such as Sweden. Far reaching legal demands have, for example, led to the closing down of the German Mannheim register¹ and the oldest continuously running psychiatric register in the world, the Norwegian register of psychosis.²

Far greater damage is likely if a recent proposal by the European Commission is implemented. Its key paragraph states that "member states shall prohibit the automatic processing of sensitive data—for example, regarding health—without the expressed and written consent freely given of the data subjects." This proposal has been described by E G Knox as "a whiff of legal pedantry as deadly as the hazards that epidemiologists will no longer be able to investigate."³

The restrictions introduced by legislators reflect their desire to give priority to individual consent at the expense of benefits to society. The purpose of this paper is to question this development by comparing the rules for epidemiology with the corresponding rules for data protection in journalism.

Aims and tasks

Epidemiologists and journalists have much in common. Both are expected to meet the public's need for knowledge and to provide information that will help individual and community decisions. Both journalism and research activities are also essential prerequisites for an open society, providing knowledge about the activities of those in power and the effects of their activities. Many epidemiologists and journalists also believe they have a duty to identify and publicise inequity in the community.

Epidemiologists and journalists use their data in different ways. While the focus of interest in journalism often tends to be an identified individual, epidemiologists are not interested in the individual as such. They need data related to an individual only to link data—for example, from an occupation register to data in a cancer register in order to analyse the risk for cancer in a certain occupation.

The two professional groups also differ in their methods and use of confidential information. Journalists get their information any way they can; epidemiologists collect their data according to strict rules and use confidential information only after special permission.

Ethical principles and rules

The Helsinki declaration requires that biomedical research with human subjects must conform to generally accepted scientific principles. This means that epidemiologists, like all other scientists must be truthful, honest, impartial, and objective.^{4,5} Rules formulated by the Board of Cooperation of the Swedish Press in 1988 require journalists to give correct news—the confidence of the general public in the media demands a correct and comprehensive news service.

A closer look at the wording of the rules for the two professions discloses important differences. While the rules regulating research are imperative and have almost no exceptions, the rules for journalism have many reservations. For example, journalists are allowed to publish information which "violates the sanctity of private life" if there is a strong public interest.

Legal and other community control

In Sweden the Secrets Act covers public documents—for instance, data collected in records and case registers in public health services.⁶ This law states that no information about individual patients may be delivered from a clinic or a health centre if such delivery, in the opinion of the responsible physician, may cause any inconvenience to the individual concerned.

The Data Protection Act has similar principles to legislation in other European countries. One provision, of special importance for epidemiological research, is that every case register must be notified to the data protection authority, the Swedish Data Inspection Board, and a condition for approval from the board is that the information is to be used only for statistical and scientific studies.

Every epidemiological project must also be approved by a research ethics committee. This is a requirement for sponsoring and publication in scientific journals. The committee makes a general ethical analysis, weighing possible ethical costs against possible ethical benefits. In this connection the issue of respect for autonomy is very important. Exceptions from the demand for informed consent are granted only if, firstly, previously established case registers are used; secondly, the demand for informed consent would seriously jeopardise the study; and, thirdly, there is maximum data security.⁴

Journalism is also regulated, but by different laws, provisions, and agreements. The Swedish Press Act 1949 (valid for all printed publications) both protects journalistic practice and imposes some restrictions.

The Data Protection Act also applies to journalists, and two conflicts have recently occurred over its application to the media. The first concerned a register which was to include the complete text of all published articles and broadcast programmes, using every word as a key word. All the data could therefore be connected with any name or other verbal concept in the register. The Data Inspection Board accepted the establishment of such a register on condition that sensitive information (regarding crime, for example) should be less accessible after a period of five years.¹⁰ However, the

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Journalists may be exempt from some data protection requirements; not so epidemiologists

Swedish Newspapers Organisation appealed to the government, and the board's decision was overruled. This appeal was also supported by a motion in parliament.¹¹

The second conflict concerned a proposal of the attorney general in 1987 that individuals should have a right to demand that sensitive information about them should be deleted from computerised media text registers established by journalists of Swedish radio. This proposal was not supported by the Data Inspection Board.¹² The government later decided that the people included in the register should be informed but said nothing about the right to erasure.

The Secrets Act affects journalism, too. In Sweden the anonymity of the provider of confidential information to the press is protected not only by prohibiting the publisher from revealing the identity of anonymous authors but also by provisions prohibiting the authorities from tracing informants.

Ethical conflicts and their present solutions

Epidemiologists give high priority to ethical rules protecting the individual. They are prepared to allow only very slight infringements on personal autonomy and privacy. Furthermore obvious violations of ethical rules will probably put an end to a scientific career. In this context society gives epidemiological research a low priority.

With journalism, by contrast, the benefits of an open society are frequently given priority over the interests of the individual. Individuals may suffer great harm, and their privacy is often not taken into account. This choice of balance is evident in serious personal tragedies occurring because of adverse publicity in the media. Furthermore, unlike research projects, journalistic activities are not scrutinised in advance, only afterwards. Violations of legal rules may be brought before a court of law. Likewise, journalists' disregard of the ethical principles and rules (drawn up by the main organisations of the Swedish press, the Club of

Publicists and the Swedish Newspapers Publishers Organisation) can be brought before a court of honour of the Swedish press, but that may be too late for the individual who has suffered unwanted exposure in the media.

The European Union proposal described earlier will prohibit epidemiologists from processing personal health data without explicit informed consent from each individual, although there are certain limited exceptions when the public interest overrides this requirement.

By contrast, member states are being advised to provide wider exemption from data protection directives for the processing of personal data by journalists working for the press and audiovisual media. This exemption is being justified on the basis of freedom of information. No such exemptions are suggested in relation to research. This means that epidemiological research will be possible only if explicitly supported by law or with special permission from the relevant data protection authority.

Conclusion

We believe we have drawn attention to a paradox. The aims and tasks of both journalism and epidemiology are in line with fundamental values in our society. But the aims and tasks of journalism—with its emphasis on an open society—are not compatible with strict adherence to the principles of individual autonomy and of doing no harm. Hence infringements of these two principles by journalism are unavoidable ethical costs in an open society.

In epidemiology there is no need to violate the principle of non-maleficence. Epidemiological research does not usually harm its subjects. But it is hardly possible to carry out case register research without some infringement of individual autonomy. Compared with the ethical costs of journalism, however, the ethical costs of case registers are modest. So if the present costs of journalism are regarded as ethically justified—and legally they are—there seems to be no good reason to be indignant at the costs of case register research.

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